

Reaching Women ^{OF} Color

Through **Ryan White CARE Act** Programs

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Chapter One

Overview

Reaching Women of Color Through Ryan White CARE Act Programs is a resource for Ryan White CARE Act grantees who want to improve their outreach and services to women of color affected by HIV/AIDS and their families. It is a compilation of successful practices from family-centered, culturally competent programs, as well as insights from women participating in them. Rather than providing case studies or endorsing any one program model, we have collected examples of what women and care providers across the country say is working in Ryan White CARE Act programs that serve women and their families.

THE CARE ACT

Since 1990, The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act has funded primary care and support services to low-income, uninsured, and underinsured individuals and families affected by HIV and AIDS. The CARE Act is administered by the Health Resources and Services Administration (HRSA) and its HIV/AIDS Bureau (HAB).

Four principles guide the mission and programs of the HIV/AIDS Bureau:

- The HIV/AIDS epidemic is growing among traditionally underserved and hard-to-reach populations.
- The quality of emerging HIV/AIDS therapies can make a difference to the lives of people living with HIV disease.
- Changes in the economics of health care are affecting the HIV/AIDS care network.
- Policy and funding increasingly are determined by outcomes.

Reaching Women of Color was developed to address the first two of these principles. HIV infection is spreading almost six times faster among women than men, and the vast majority of these infections are among women of color. While new HIV therapies can dramatically improve the lives of people with HIV disease, many studies raise concerns for women. Women are less likely to be prescribed state-of-the-art therapies, and many of them are also less likely to be able to use the drugs successfully because of multiple stresses. This document offers CARE Act grantees ideas for reaching this underserved group and providing the kinds of services they need to get the most out of the best available treatments.

INFORMATION GATHERING

The practices and approaches we describe are highlights from a study conducted by the Community Research Group (CRG) at The Joseph L. Mailman School of Public Health of Columbia University and the New York State Psychiatric Institute. HRSA asked research teams around the country to answer this question: “How well is the Ryan White CARE Act serving the needs of minority women?” In response, CRG embarked on a two-month intensive study of programs for women of color living with HIV/AIDS in five cities: New York, Los Angeles, St. Louis, San Antonio, and Miami.

The CRG research team analyzed care situations from all sides by talking to planners, providers, and individuals affected by HIV and AIDS. They found that while exemplary programs and services for women of color living with HIV/AIDS are not the norm, they do exist and can serve as models for the entire care system. In that spirit, we describe an array of such practices for women living with HIV disease.

WOMEN AND AIDS TODAY

Between 1985 and 1994, the number of AIDS cases among women tripled. Overwhelmingly, these have been women of color: 77% of women living with AIDS are black or Latina. Therefore, throughout this document, “women living with HIV and AIDS” will refer primarily to women of color.

The upward trend in HIV/AIDS among women shows no sign of abating. In 1999, for the first time more females than males were diagnosed with HIV among 13 to 19 year olds—six out of 10 new HIV infections in this age group. Among 20 to 24 year olds, young women account for just one-third of all HIV infections ever reported but 44% of new infections reported in 1999.

Many women with HIV disease are raising families in poverty. Many have also lost husbands or partners to AIDS. They may have trouble finding quality medical care. The demands of caring for their children and families also may limit the extent to which they participate in their own care. Family-centered, culturally competent programs for women acknowledge the reality of these women’s lives and offer them the comprehensive care and services they need—for themselves and their families.

As the number of women living with HIV and AIDS grows, so does the need for a responsive continuum of care. This document is intended as a resource for CARE Act grantees who wish to explore their own role within such a continuum of care.

DOCUMENT OVERVIEW

Chapter Two, “Family-Centered, Culturally Competent Care for Women Living with HIV and AIDS,” reviews the fundamental principles underlying comprehensive systems of care and support for women living with HIV disease and their families. Such care is tailored to the needs and choices of the individual within the context of her family, culture, and community. From the earliest days of the epidemic among women, successful programs for women living with HIV/AIDS have incorporated these principles in their design, operation, and evaluation.

Chapter Three, “What Is Working?” examines successful practices that Ryan White CARE Act grantees are using to meet the multiple needs of women living with HIV/AIDS and their families. One-stop shopping that balances these multiple needs, a welcoming atmosphere that treats women in a holistic fashion, services tailored to women’s cultural and individual identities, and political, personal, and community empower-

ment all characterize exemplary CARE Act programs providing women-specific care.

Chapter Four, “Consumers and Providers Speak Out,” offers the views of women living with HIV and of CARE Act grantees serving women and families. Their experiences parallel what HIV-positive women and their care providers have long advocated through consumer/provider partnerships. We are heartened that so many

CARE Act grantees are joining with HIV-positive women to develop a comprehensive continuum of care in communities across the country.

Chapter Five, “Where to Find Out More,” lists CARE Act grantees that participated in the study and are willing to share information about their programs. Contact information is also provided for AIDS Alliance for Children, Youth & Families.

Chapter Two

Family-Centered, Culturally Competent Care for Women Living with HIV and AIDS

This chapter explores family-centered, culturally competent care as the foundation for Ryan White CARE Act programs that serve women and their families.

FAMILY-CENTERED CARE

Because most women living with HIV/AIDS are of childbearing age, HIV infection among women is most often a family disease. Since 1994, the majority of HIV-positive women in the U.S. have become infected through their male partners. This means that whether or not she has children—and whether they are infected or affected—a woman with HIV disease will often have multiple and conflicting care demands. For many such women, their own health will not be the top priority if they are forced to choose between taking care of themselves or getting their children, spouses, partners, or other family members the care they need.

Programs serving women living with HIV are most successful when they are family-centered, offering women care and support that meets their self-identified needs within the context of their families—care that reflects their concerns, priorities, and choices. For women living with

HIV disease, family-centered care is also comprehensive. Comprehensive care encompasses:

- primary care;
- HIV/ AIDS care;
- reproductive health care;
- mental health care, including counseling and social support;
- SSI, welfare, and other economic support;
- homemaker services;
- housing;
- drug treatment; and
- a full range of social services such as family support, transportation, job counseling and placement, and permanency planning.

A continuum of care can be fully realized only through partnerships between women and their care providers, both at the individual and system levels. Women living with HIV/AIDS have been instrumental in defining such continuums of care, where they exist, and these partnerships are an essential element of family-centered care.

CULTURAL COMPETENCE

The United States has always been culturally diverse, although this diversity has not always been a part of our national identity. Neither has it always been an aspect of professional training for health care and social service providers or part of the design, implementation, and evaluation of programs and services. In recent years, however, the fabric of our nation has increasingly come to be recognized as a rich tapestry woven from threads from an array of cultures that make up our people. This diversity has been challenging the health care system to change to reflect the reality of the people who use it.

Initially, programs and providers sought merely to become culturally sensitive, aware of the diversity of the people they served. But today, there is a more promising goal—cultural competence—a proactive concept that transcends cultural awareness and sensitivity. Cultural competence can be defined as the ability to work effectively within and across cultures.

Becoming culturally competent requires first overcoming the conventional wisdom that “all people are alike,” a difficult barrier for many

well-brought-up middle-class professionals. This notion, while well intentioned, generally has resulted in programs and services designed for the dominant culture and characterized by the belief that helping approaches used by the dominant culture are universally applicable and will benefit all people regardless of race, ethnicity, or culture.

In culturally competent CARE Act programs, administrators and care providers develop service options that match the language, culture, and spiritual beliefs of the women and families in their service areas. Among the most common provisions are:

- hiring staff from the cultures and communities being served, including bilingual staff;
- translating forms and other written materials;
- offering services in locations within the community where women gather; and
- providing staff with systematic, continuing training on cultural perspectives.

Table 1, “The Fundamentals of Cultural Competence,” illustrates the extent to which honoring

TABLE 1 THE FUNDAMENTALS OF CULTURAL COMPETENCE	
Honoring cultural diversity—racial, ethnic, religious, and socioeconomic—by:	
<ol style="list-style-type: none"> 1. Recognizing the power of culture in shaping values, beliefs, and experiences. 2. Examining one’s personal and cultural make-up, and learning how they affect interactions with others. 3. Learning about the cultural norms of the communities with which one interacts, and about the extent to which individuals share these norms. 4. Approaching each family on its own terms, with no judgments or preconceptions, and enabling each family to define its own needs. 	<ol style="list-style-type: none"> 5. Helping families navigate the health, education, and social service systems of the dominant culture. 6. Acknowledging that many families and communities have experienced racism and other forms of exclusion and disempowerment, experiences that are likely to affect their interactions with service providers and service systems. 7. Eliminating institutional practices that exclude people from services because of race, ethnicity, sexual orientation, beliefs, or practices. 8. Building upon the strengths and resources of each family and community.
<p><i>Source:</i> M. McGonigal & D. Jones, Institute on Cultural Dynamics & Social Change, Rochester, MN.</p>	

cultural diversity affects every aspect of care and services.

EMPOWERMENT AND BUILDING ON STRENGTHS

Empowerment has long been held as key to both family-centered care and cultural competence. Empowerment, however, is sometimes misunderstood to mean that service providers give or bestow power on their clients. That is not the case; the power is theirs by right.

In the context of CARE Act grantees, empowerment can be defined as interacting with consumers in such a way that they maintain or acquire control over their own lives and attribute their successes to their own and their community's strengths, abilities, and actions. Ryan White CARE Act programs empower women when they:

- share complete and unbiased information;
- avoid unilateral decision making;
- offer an array of services, resources, and supports; and
- honor the choices women make for their families and themselves.

Building on existing strengths—and creating new ones—is also key to the practice of family-centered, culturally competent care in Ryan White CARE Act programs serving women living with HIV/AIDS and their families. Learning to recognize the strengths, competencies, and resources present in all families, cultures, and communities is an essential foundation for successful programs for women.

Chapter Three

What Is Working?

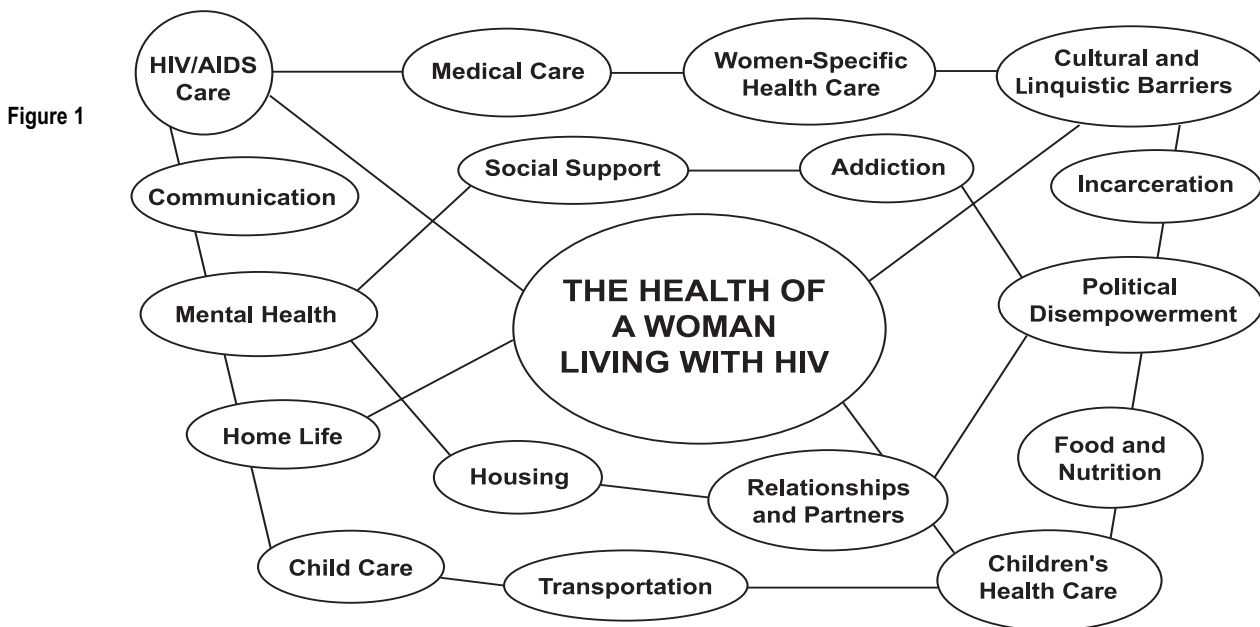
CARE Act grantees providing services for women and families living with HIV and AIDS have experienced both remarkable successes and disappointments in tailoring the care clients receive to their individual needs. This chapter describes essential elements of programs that work successfully for and with their clients, with particular attention to services aimed at bringing into care populations of women who have been underserved by the traditional health care system.

UNDERSTANDING THE HIERARCHY

Exemplary care providers know that programs that work for women living with HIV and AIDS are

based on an understanding of what women want and need for themselves and their families. Women of color living with HIV often identify a long list of service and support needs, only a small portion of which relates to their HIV-positive status. The most successful programs found in the CARE Act study were those that understood this hierarchy of needs and addressed the big picture in partnership with the women they serve.

The hierarchy of needs for women living with HIV typically arises from a multitude of issues acting together (see Figure 1). They may be dealing with medical issues, women-specific health problems,



cultural and linguistic barriers, a lack of open communication, low levels of social support, political disempowerment, and issues in the home, such as lack of adequate food, housing, child care, and transportation. Addiction, violence and abuse, insufficient support services in jails and prisons, and mental illness further complicate the lives of a number of women living with HIV and AIDS. In addition, because they are usually the primary caregiver in the family, women typically take on responsibility for managing the care of everyone in the family, as well as their own.

Listening to women’s priorities is essential. As CARE Act grantees, we cannot properly care for women unless our priorities parallel theirs. If women put children and family first, then we must help women with their home lives first. If women put a lower priority on medical treatment than on daily concerns, then service providers must be attuned to those other needs before they will be able to help women get into care.

This is the crux of empowerment: helping individuals identify their own needs and offering

comprehensive services and support from which they can choose to meet those self-identified needs. Conversations between clients and providers and community-level needs assessments can help CARE Act programs achieve this through a team approach in which care providers meet women where they are and create with them an agenda for treatment and care.

Working on fundamental, structural issues first—such as housing or family strengthening—often indirectly addresses other issues as well, such as a lack of social support. Help a woman speak out about her needs in medical settings, and she soon may be receiving culturally competent care. Help families learn communication skills around living with HIV, and a stronger support system may develop.

Women living in high-risk circumstances typically are not out in force publicizing how HIV is affecting them. In part, this is because women are not a geographically or culturally concentrated community of their own. CARE Act grantees and other community-based organizations can advocate on behalf of women and

A HIERARCHY OF NEEDS		
Health and Medical	Economic and Social	Family and Home
Primary Care Care	Medicaid/Medicare	Children’s/Spouses’ Health
HIV-Specific Care	Cultural Barriers	Communication
Women-Specific Care	Language Barriers	Relationships
HIV Treatments	Transportation	Partners and Sexuality
Alternative Treatments	Addiction/Recovery	Housing
Mental Health Care	Incarceration	Child Care
Support Groups	Political Disempowerment	Food and Nutrition

HELPING WOMEN MANAGE A HIERARCHY OF NEEDS

Understand the priorities of women and their families.

Ask, listen, and create a continuum of care that matches these priorities.

Help women create a stable base from which they can work.

Strengthening the foundation of a family and home enables families to make maximum use of their own resources.

Empower women.

Help women speak up on their own behalf and identify what they want and need. Support their participation in care planning and decision-making.

their needs in the larger political arena. In addition, service providers can help empower women by offering them opportunities to learn advocacy skills and inviting them to join in program planning and decision-making processes.

Ryan White CARE Act programs throughout the country are working to help women live successfully with HIV and AIDS. Following are descriptions of important aspects of their programs and services that can be incorporated into any local system of care.

ONE-STOP SHOPPING

Exemplary programs often choose to meet women’s needs by providing “one-stop shopping,” a network of services for women and their families under one roof, or as close to it as possible. One-stop shopping allows women to get access to care and services in ways that work for them. Both the CARE Act grantees studied and the women they serve see one-stop shopping as much more than a popular catch phrase. To them, it is guiding principle.

The one-stop shopping model typically includes a wide range of medical care—OB/GYN, HIV-specific care, pediatrics, mental health services—as well as links to case management, drug and alcohol treatment, housing, food stamps, and other income support (see Figure 2). Women say

they especially appreciate programs with areas where their children can play or be dropped off for a few hours so that they can take care of their own needs.

There is no one best model for one-stop shopping. Some programs cluster services within the perimeter of a medical campus or large hospital complex. Others fit the same range of services within tightly packaged, small-scale community-based operations. The former are at times intimidating and difficult for women to maneuver through, while the latter are often more comfortable for consumers. Families in some programs spend entire days shuttling from one department to another on a medical campus, while other medical center programs bring an array of health care providers into the clinics so that the women do not have to move from one place to another.

ATTENTION TO ATMOSPHERE

CARE Act grantees that offered women- and family-centered atmospheres are highly acclaimed by women in the study. They especially appreciate the following:

- facilities that resemble homes, with living rooms, kitchens, patios, couches, and libraries;
- warm and accepting programs, with a quality women described as practical, yet nurturing;

Figure 2

THE ONE-STOP SHOP



- ◆ Primary Care Physician
- ◆ HIV Specialist
- ◆ OB/GYN
- ◆ Pediatrician
- ◆ Substance Abuse Treatment
- ◆ Psychiatrist
- ◆ Case Manager
- ◆ Support Groups
- ◆ Housing Assistance
- ◆ Medications (ADAP)
- ◆ Food Stamps
- ◆ Welfare Representative
- ◆ Child Care



- treatment advocacy to help women learn about medications and about how to talk to doctors about drug regimens;
- quarterly socials that bring families of clients together to get to know each other and to learn about programs that help the women in their lives;
- programs that offer concurrent support to their children;
- peer retreats that allow women to get away together and bond with others going through similar times; and
- activities such as crafts workshops and massages—centered around treating women like women and not simply patients.

All of the above characteristics exemplify a holistic approach to women's care that acknowledges the need for support in their daily lives.

The creation of communities in these programs allows women to pool their resources, making them stronger voices in the struggle to get resources outside the program. At one CARE Act program within a hospital, for example, HIV-

positive women are brought together through a peer support group; the women and case managers elected one member of the group to the local Ryan White Planning Council. She was then trained as a consumer advocate to represent the interests of the other women and families. In that role, she is able to exercise her vote on decisions that set priorities for funding HIV services in the community.

AIMING FOR FIT

Women in the study say they are most comfortable in settings attuned to their culture and language, and having Spanish-, French-, and Creole-speaking case managers is a source of pride for several CARE Act grantees. Both families and providers view case managers from backgrounds similar to their clients as most capable of anticipating barriers to a true continuum of care and of finding alternatives to traditional approaches that are more in tune with the way the women live their daily lives.

One case manager was able to find a new approach for a support group for Haitian women, a group that had seemed destined to fail. She invited HIV-positive teens to speak to

women who had been reluctant to approach AIDS-related topics with their peers. The teens disclosed their status to the group and talked about living their lives with the virus. They were able to break down walls and lessen the stigma of their situation. In following meetings, women took turns disclosing to the group.

Both cultural and individual differences structure family priorities and the community resources available. Knowledge of these differences leads to a much greater chance of success. For example, in the African American communities in the study, grandparents often take on the role of caregiver for children when parents are overwhelmed by their own health problems. This is more difficult for the Hispanic communities visited, where the extended family is more likely to be spread out geographically. Understanding cultural norms and family structures helps CARE Act grantees understand the options available to their clients.

TAILORING PROGRAMS TO CLIENTS

- Staff who speak the languages of women in the community.
- Staff who share women's culture and ethnicity.
- Staff who live with HIV/AIDS.
- Educational materials and treatment information offered in as many languages spoken in the community as possible and in a variety of formats.
- Counseling peer groups and other supports that women choose.
- Treatment regimens matched to the way individual women live.

Empowerment

CARE Act grantees are increasingly recognizing the importance of consumer advocacy and offering women opportunities to be vocal about their needs. They are sending clients to conferences, meetings, and planning bodies to take part in the decision making that determines local and regional agendas for HIV services. Consumer representatives also are attending training institutes at which they share information and learn about living with HIV and AIDS, new treatments, building networks, and overcoming barriers—all with the goal of bringing such information back to their local communities. Leadership training and empowerment are major themes at many training institutes.

AIDS Alliance for Children, Youth & Families is participating in one such effort through our Consumer Education Center, supported in part through a cooperative agreement with HAB/HRSA. An exciting feature of the Center is the Consumer Training Corps, a group of consumers who are participating in an intensive train-the-trainer program that equips them to share their knowledge, information, and skills with other consumers.

Empowerment arms women with knowledge about the choices available to them. Women know what to ask for to better help themselves and their families, and relationships with providers consequently may become less challenging. However, women/provider interactions may also become strained when women become stronger advocates for themselves and their families and communities by voicing concerns about their care or about the health care system more broadly.

Empowerment is an important concept within personal relationships, as well. Women who are empowered are better communicators of their fears and needs and more clear about their choices. They are able to discuss problems within relationships and approach topics that were previously taboo. In communities that do not openly discuss sexuality, empowerment can open up the new lines of communication that are necessary to prevent HIV infection. As more individuals become adept at holding such discussions, communities learn to take responsibility for these issues and bring the conversation to a wider audience.

REACHING WOMEN LABELED “HARD TO REACH”

Some women living with HIV are especially at risk for receiving inadequate care or no care at all. Many CARE Act grantees are tailoring their outreach and education to women outside of or alienated from the care system to let them know that care is available to meet their needs.

Substance abuse is a daunting hurdle to quality care for women living with HIV and AIDS. Programs that target addiction typically avoid taking on HIV and vice versa. Each is viewed as overwhelming in its own right. Many programs say they cannot handle both and end up ignoring one or the other.

A number of exemplary CARE Act grantees, however, tackle addiction as a part of treating women holistically. One residential community provides housing and basic services such as food, medical treatment, and support services for entire families, giving women a stable foundation that allows them to focus on their recovery. Once the women are clean, the program gets them and their families into safe housing to help them sustain their success. This treatment

community is appreciated by its members and claims many successes.

Mental illness is an additional roadblock many HIV-positive women face, because mental health care is underfunded in general and rarely tied into HIV services. All too often, such care is seen as ancillary. One CARE Act program studied was created specifically to fill this gap. Every woman is screened for a variety of mental health problems—including addiction and a history of violence and abuse—and offered appropriate counseling and therapy. The program, which operates within a major medical center, uses a service integration approach that encompasses and coordinates health care, mental health care, and social services. Both staff and clients—well over half of whom report a history of victimization or abuse—think this program should be replicated across the country.

Women in jails and prisons often receive less than optimal care. They typically have minimal access to information and are limited to the providers and programs contained within the confines of the prison system. One community-based CARE

Prisons and jails, designed to confine and punish people, many of whom are generally poor and without influential outside advocates, have not voluntarily provided the extraordinary levels of health services patients with HIV require. Prisons have often escaped outside attention to serious failures of care. (Kantor, 1998, p.8)

Act grantee in the study bridges this gap with case managers who visit incarcerated women living with HIV/AIDS who are about to be released back into the community. The case

**CARING FOR INCARCERATED HIV-POSITIVE WOMEN:
WHAT RYAN WHITE GRANTEES CAN DO**

Inform and Educate

- Recruit peer educators who are now outside the system to answer questions and teach lessons on living with HIV within the system.
- Bring in newsletters and publications from advocacy groups and organizations. Encourage letter writing and submissions to these publications.

Promote Open Communication

- Involve everyone in discussions to reduce stigma and secrecy.

Offer Training to Prison Care Providers

- Advise on how to create support groups within jails and prisons for HIV-positive women.
- Advise on ways to help women learn about

antiretroviral therapy and make decisions about treatment.

Help HIV-Positive Women Plan for Life After Incarceration

- Start by informing women of their choices for care and services.
- Collaborate with other organizations and groups that will serve the women outside the jail and prison system, and hook women into programs and services that they can use right away.
- Assign an advocate or case manager for each woman who will serve as a guide on the outside and can help women design plans for meeting their medical and psycho-social needs.

managers provide information and connect women to halfway houses and a range of support services that help them avoid returning to situations that led to their imprisonment and provide a foundation for rebuilding their lives. A number of grantees offer such concrete help with pre-release planning, making sure that women have links to the services they will need when they get out. Often, they help women fill out eligibility paperwork for health and social services programs and ensure that women on antiretroviral treatment regimens have several weeks supply of HIV/AIDS drugs to last them until they can get a steady supply in the community.

Developing services for incarcerated and soon-to-be-released women offers CARE Act grantees remarkable opportunities to reach women the term “underserved” hardly begins to describe. These women are in dire need of services and support, and there are many of them. The rate

of AIDS among women in jails and prisons is 12 times higher than in the general population. At the end of 1997, 3.5% of female prisoners in the U.S. were known to be HIV positive. In New York City, as many as 26% of women in the jail system are HIV infected. One-third of women in prisons across the country have used needles to inject drugs. Over one-third have a history of sexual abuse. Clearly the need is immense; its enormity challenges more CARE Act grantees to get involved with serving HIV-positive women who are in jails and prisons in their own communities.

There are as almost as many ways to begin as there are local programs. Some CARE Act grantees approach the jail or prison directly. Others go through their state or local health departments. Still others gain access through links with church groups. The services these grantees offer are as varied as the ways the

Engaging Underserved Women In Care

- Acknowledge and deal with the competing issues HIV-positive women and their families live with every day.
- Create programs and services that treat HIV as one challenge among many related ones such as drug addiction mental illness or incarceration.
- Find women with unmet needs through outreach to churches schools and other community organizations and through places where women congregate.
- Organize social activities like fairs and parties where community members can get together. Incorporate prevention messages into these activities.
- Use peer educators to make women more comfortable with the care and services in which they participate. Buddy programs can offer women a knowledgeable guide through the system.
- Follow women through the system. Don't let them fall through the cracks once they've been connected to care. Keep tabs on consumers to the extent they permit—make regular phone calls and follow-up on missed appointments.

programs begin. Some offer training and technical assistance in HIV clinical care to prison medical staff. Recognizing the power of peer counseling in an environment in which trust comes hard, other community-based programs partner with HIV-positive inmates to help them coach other women in prison on how to take care of their health and adhere to complex treatment regimens.

For more information about serving women living with HIV/AIDS in jails and prisons, see AIDS Alliance's new publication, *Supporting Incarcerated Women with HIV Disease*.

Sex workers and other women who exchange sex for money or drugs are often alienated from the health care and social service systems, yet they are at very high risk for HIV disease. Community-based programs are reaching these vulnerable women through a variety of street outreach and store-front programs that meet the women in their own territory and offer health care and other concrete support tailored to individual needs.

CARE Act programs serving sex workers invest time and patience in establishing the trusting

relationships with clients that are especially necessary with women who are very likely to have experienced domestic abuse, child physical and sexual abuse, and other victimization. Sex workers also have high rates of substance abuse and legal difficulties. All of these circumstances can act to keep women out of care and require multiple and sustained efforts on the part of care providers to engage them.

BUILDING BLOCKS

The components outlined in this chapter are building blocks for successful programs for HIV-positive women and their families. CARE Act grantees that are welcoming and that offer one-stop shopping, empowerment and advocacy training, peer support, diverse staff for diverse clients, and attention to problems that compound women's lives are vitally necessary in the communities hardest hit by HIV. Novel approaches to treating women and families holistically are much more likely to meet them where they are and reach those who have not been able to use the care system in the past. CARE Act programs such as these can be models for the entire system of HIV/AIDS care.

Chapter Four

Consumers and Providers Speak Out

Throughout the CARE Act study, women and providers shared stories about what works and what doesn't in the current system of care for women living with HIV and AIDS. The following statements and vignettes, which address the categories of needs outlined in Chapter Three, illustrate how CARE Act programs are creating women-centered, culturally competent services and programs tailored to pressing needs and shaped upon existing successes.

SPEAKING OUT ABOUT BALANCING MULTIPLE ISSUES

Many CARE Act grantees attest to the multiple issues women and their families must deal with in addition to HIV. From the most basic needs, such as housing and food, to the most specific, such as female Spanish-speaking gynecologists, women, families, and providers describe what it takes to create a real continuum of care and where the present system falls short. In addition, they discuss the priority women give to day-to-day urgent needs for themselves and their children.

One provider from a program that was meant to be comprehensive, regrets the gaps. The program:

... does not include enough about multiple issues, such as substance abuse, poverty, literacy, and education. Minority communities are dealing with so many other issues, and HIV is only one in a whole world of others. But this is one we can overcome.

Another CARE Act provider further illustrates this point. Most of the women:

... are the primary caretakers of their families and the primary income earners. They are undereducated and underemployed. They not only have to face disclosure issues, but also issues related to race and poverty. Daily, they have to stack all these issues on top of one another and sort out what they will address. Here they are allowed to incorporate all these things, whereas if they were just going to their doctor's office, they would not mention that they don't have a phone.

One woman talks of needing assistance on days when it all seems too overwhelming. She isn't asking for a specific service. Hers is a general call for help in managing everything on her plate:

We need someone that we can call up and say “Can you just help me today?” Not an ongoing thing, but something in place to help me today. I have energy one day, but then there are those other days. On good days you want to participate and do it on your own, but you have bad days or months and that contributes to your state of mind. Then you get depressed and don’t go out of your house and you isolate.

Another CARE Act provider describes how her clients fit HIV infection into their daily struggles:

Our patients are operating with so many weights hanging off of them, that HIV would just be one more. So in a very practical, day-to-day kind of thing, you can understand their approach. There is a certain hopelessness about this. A woman’s philosophy, and I think this cuts across all classes, is generally to do the thing that is in front of you. It is not necessarily a powerless position; it is powerful in that you know how to manage all of these things. That is a life approach that is very antithetical to preventive primary health care.

SPEAKING OUT ABOUT ONE-STOP SHOPPING

Convenience is a priority when women living with HIV juggle multiple problems. Taking care of the needs of every family member, especially children, proves extremely challenging for women living with HIV when services are not coordinated. This is even more troublesome for women with children when some are infected and others not and they are forced to seek different kinds of services in different places. Although widely seen as a desired outcome, women and providers say one-stop shopping is hard to achieve. One woman living with HIV

hails her CARE Act program as “one of kind” because it has doctors, nurses, transportation, case managers, a peer program, a back-to-work program, a chaplain, youth outreach, a clothing room, lunch, retreats, and support groups all under one roof.

A CARE Act provider gives an example of what women typically go through when seeking care for themselves and their families. The provider puts herself in a client’s shoes and describes what her situation might be like:

As a black woman with children, I am trying to do the best I can, but I have three children who are not in day care. And if I am trying to keep the appointment with one of the children or myself, I have to take everybody. And I can’t take the two because they are affected, not infected, so I am not going to go. This is difficult, and these are the issues that need to be addressed.

A consumer advocate living with HIV discusses her ideal:

Everything in one building that both women and children need, including welfare and housing services.

In addition, she says, mental health and substance abuse services should not just refer women out. Mental health care and treatment for addiction should be included within the core services offered at any comprehensive center that serves women and families living with HIV/AIDS.

The following vignette offered by a CARE Act provider further describes how difficult it is to juggle multiple needs:

You are a woman who is infected and you have two kids. One is infected, one is not. You have got to go to provider A for your primary care for your HIV and to provider B for your outpatient substance abuse treatment that is on the other side of the county. Your infected child has to come here to the clinic for infected kids. But your affected kid needs to go to a health department clinic for his immunizations. One of those kids needs psychological services. You as a woman have to orchestrate all of your service providers and all of the service providers for your kids, and you've got to haul them around almost every day. Plus you've got to go to the store, plus you've got to get your meds, plus you've got to go to the welfare department, plus, plus, plus. It's mindboggling.

An HIV-positive woman imagines how easy life could be with coordinated services that were located close to one another:

Can you imagine how wonderful it would be for me to come here today to do the hotline, attend a support group, go to the food bank, and see someone medically? And to go someplace relaxed and homey? And in close proximity?

SPEAKING OUT ABOUT ATMOSPHERE

Many HIV-positive women say they could not be where they are today without the CARE Act programs where they receive care. These highly valued programs most often are homey and welcoming. In many instances, they provide a "second family" for the women they serve, including support groups where women get together with their peers and focus on themselves holistically and not simply on their illness. While women view these kinds of services and

programs as important and worthwhile, they say that funders often do not view them as essential.

One client speaks of her support groups and how they help build self-esteem by making women feel less like outsiders:

The support group works as a self-esteem building tool. Nobody wants to pay for the supplies for these workshops, even though this group is hugely successful in bringing women out of isolation, connecting them with each other, building camaraderie, a sense of community, all of the things that women don't have because we are not geographically solidified into one area.

Another women living with HIV discusses the comfort and inspiration she receives from her peers:

You come out of the groups feeling so relieved that you are not the only person with HIV, that there are also other women with HIV. The fact that you are really not going to die, don't prepare yourself to die, prepare yourself to keep on living.

Women describe the most important aspect of one program as feeling as if they have a family there, "because there is a lot of getting to know others and sharing with others." One comments that when she was first diagnosed she went to the hospital for treatment. There she was "treated like trash," but at her program she receives "hugs and kisses. People know my pain and treat me like I am human."

SPEAKING OUT ABOUT AIMING FOR FIT

Offering programs and providers that match the specific cultural and linguistic backgrounds of their clients takes special targeted effort. In the CARE Act study, diverse communities within each city testified to the varied culture-specific needs within a system of care. Women living with HIV/AIDS are sprinkled throughout every community in each city. Because client priorities, knowledge, and understanding differ from place to place, these differences must be accounted for in the way CARE Act grantees design and operate their programs within a geographic area. A case manager describes ideal services as:

... provided in a place where people go anyway, with people who can relate to them and speak the language. A cultural group for kids dealing with culture shock would be good, too.

Multiple Languages and Cultures

Educational materials, videos, and treatment information should be available in the variety of languages present in the geographic community or catchment area. Without the appropriate material available, rumors may start and spread within communities that are linguistically or culturally cut off from the most current information. In one city visited for the CARE Act study, a radio program for the Haitian community was spreading false information about HIV and AIDS, and a second program was launched to counter the rumors with factual information. Misinformation feeds the stigma and secrecy that often shrouds individuals living with HIV/AIDS.

A consumer advocate discusses how, especially in the African American community, an older generation of grandparents needs help as they

take on even greater caregiving roles when AIDS affects their children and grandchildren. She says that grandmothers are from “the old school and don’t respond to preaching from doctors,” but instead want advice in terms they can relate to. Older women who are themselves living with HIV face many special challenges in finding appropriate care and services, as many programs are geared toward women of childbearing age.

Faith and HIV

Faith and religion are heavily woven into the fabric of many communities of color. There is a tremendous opportunity for religious institutions to help bridge the gaps in knowledge, understanding, and behavior about HIV and AIDS. Many people living with HIV/AIDS who come from these backgrounds believe that fate and God are responsible for what will happen to them, a belief that counteracts many prevention messages and testing efforts.

One CARE Act program studied arose from a church group to create a network of HIV services, child care, and counseling, both pastoral and nonpastoral. They advocate for church leaders to be open with their communities and congregations about HIV and to provide much-needed encouragement to those living with HIV disease. One group invited a famous church leader and politician to participate in an event focused on getting tested. He got tested and shared his results and concerns with the community, encouraging others to follow his lead.

About the role of community institutions in aiding people living with HIV, one CARE Act provider suggests:

Individuals cannot do anything with good information if their social environment does

not support them. If the church and the neighborhood are failing you, for example, the information will go right through you.

One woman living with HIV discusses what being African American means for her illness:

There are elements about being an African American woman in an African American family and community that impact how women with HIV take care of themselves. In general, in the black community when there is a person with HIV or a substance abuse problem in the family, people don't talk about it; they push it to the side and pray that the person will make it.

Another CARE Act grantee emphasizes the importance of attending to cultural norms and values when designing programs:

We need to look at people's networks. We need to understand how Haitians and Hispanics understand services and what they are living with. Parents have shrunk back because they don't see others like them, and services are not culturally accessible. The communities are closed, and you need to speak their language in order to hear them.

An HIV-positive consumer advocate talks about understanding where clients are coming from in order to serve them well:

Professionals need to be trained about the issues minority men and women with AIDS are dealing with. They need to understand where their client is psychologically and not treat women inappropriately or else they will lose them right away.

SPEAKING OUT ABOUT EMPOWERMENT

Empowerment is already a goal of many CARE Act programs serving women with HIV and AIDS. The gender power structure, discrimination based on race and ethnicity, economic disparities, and the stigma attached to HIV all contribute to the disempowerment of women of color living with HIV/AIDS.

Political Empowerment

Women are not a traditionally politically empowered group, and women of color are hardly a "group" at all. The fight against HIV and AIDS had its primary roots in the gay white male community, a group that was remarkably successful in organizing and mobilizing itself to fight the epidemic. Therefore, many programs and services for people living with HIV grew out of what were once gay activist organizations, and such programs were tailored to fit the needs of their founders. Because of these origins, the majority of AIDS service organizations have not been designed with women's needs in mind.

The effect of this history is two-fold. First, the care and services available to women are often not what they need and want. Second, the struggle for funding to change the system is that much harder. Battling for money with well-trained activists has proven mostly unsuccessful. One CARE Act provider discusses the need to level the playing field:

So much of your money is going to agencies that have little programs within their agencies that help women. But you are not giving specifically for agencies that are women specific and ... are created by women and run by women who are actually living with HIV. And who else better than those of us who are actually living with HIV can actually say what we need?

Women are realizing the need to take part in these conversations. One woman living with HIV says the following about the political process governing funding decisions:

We need more representation of women on committees when different things are coming up and decisions are being made. Our health care is being based on how men have been taken care of in the past, and we are quite a bit different. We need to have a larger say-so on what is being decided.

Because women have been underrepresented in HIV/AIDS decision-making bodies, they have not been able to direct funding toward much-needed services. A CARE Act provider comments on how difficult this is to change:

Our funding bodies were started by gay white men, and they funded service categories such as housing and food, but not the other services we provide for women, and people don't want to give up their money. The system works fine for them, and they want to keep working in this system.

An HIV-positive client voices his complaint about the importance of communication and the decisions that are often made without it:

Positive people need to be involved in leadership positions. Everyone needs to put their thing in the soup, and then we'll have some real good soup. There needs to be an opportunity to speak up and explain and move beyond the things that are limiting what we can do about this epidemic.

Several CARE Act programs have taken on empowerment as a theme in their efforts to help women in the struggle to be heard. Training

institutes that teach lessons on activism and the political process are growing in popularity. HIV/AIDS programs are invited to send consumer representatives to these institutes, which can sometimes last a week or two. An administrator of a large AIDS program at a major medical school says the following about the need for empowering communities to accept and deal with HIV:

If you won't own diabetes and you won't own hypertension as a community plague, how do you think you'll get to owning HIV? Outreach can change that, but I think you have to persuade people politically. You have to persuade people that this is connected to the whole political posture of minority people in America. Recognizing it and holding on to it and saying this is ours and we can solve it is empowering. It is not a negative thing.

Other CARE Act providers and administrators discuss strategies for helping women strengthen their voices. One such administrator describes his agency's efforts and the results:

We work closer with clients than any other agency. We do strategic planning. We brought people in treatment together and broke them down into different workshops. We sat with them in small groups and said, "We want to plan services that are appropriate for you but we don't know what to do because we are working in a vacuum. What do you need? What do you want?" We registered them to vote. Then we started taking them over to the board of supervisors and had them sit down with health deputies and talk about how drug treatment had made a difference in their lives in dealing with HIV. A client committee was formed. And the

clients then thought they should be co-chairs of the task force.

Personal Empowerment

Empowerment works within the confines of relationships as well. Many women of color have struggled through gender power relationships that have left them vulnerable to the transmission of HIV. About the power of women within their own communities, one CARE Act provider says:

Women do not feel empowered. They do lots for their children and partners and put themselves last. There is culturally no power for women over sexuality in many communities. What should a woman do when sex and nondecisions are forced on her? Harm reduction must start young, and women must be given power early. They need to be taught more about relationships and self-esteem.

A consumer advocate who sits on a local Ryan White Planning Council says the following about education and empowerment for one group of women:

Women are caught in a bind because they do not know how to address issues of safe sex with their partners when they come back into the community from the prison system. They have fears of abuse and rejection and can't communicate their concerns to their partners. We need to educate men and women to build the esteem and skills they need.

Many women living with HIV also do not feel empowered within their relationships with health care providers. This can lead to stymied communication, resulting in inappropriate care. About the effect of women's perceived power on successful communication, a CARE Act provider suggests:

Women don't take the initiative with what they don't receive, and they don't see themselves as having the power to. It would be ideal for Hispanic women to go to their providers and ask for help because of their partners' activities, but this just doesn't happen. This would be a form of betrayal in their minds. There is ... a mentality whereby they are numb to what is happening to them.

Community Empowerment

Women living with HIV and the CARE Act grantees who care for them cite lack of communication as an overwhelming problem in preventing and treating HIV/AIDS in communities of color. In general, they say, people do not speak openly about sexuality, which leads to an underappreciation of risk for HIV in relationships. Furthermore, communities do not openly acknowledge that the disease is a real issue that desperately needs addressing.

All of this leads to increased stigma associated with HIV/AIDS and leaves women and families living with HIV isolated in secrecy, without the support they need. Many providers and activists insist that media campaigns are the necessary tool for opening up lines of communication within communities dealing with HIV and AIDS.

An HIV-positive African American woman says the following about opening up communication:

We need to intensely educate kids as they grow up. We need to be open about the need to be educated and connected and know about sex and all of the related issues. They will be around when we are not, and we need to prepare them. Get the message everywhere: on buses, on the Metrorail, and on billboards.

Closed conversations about sexuality lead to a high proportion of unrealized risk in communities of color. A provider speculates about this:

African American men tend not to attach themselves to the bisexual label, even though they are participating in the act. This, along with stigma and denial, contribute to the spread of HIV. In the black community, women ignore and deny the fact that many of the men they are involved with have had or are having sex with men. Many men become infected in prison and resume heterosexual lifestyles when they return to the community; these men do not see themselves as at risk.

Several CARE Act grantees and consumer advocates stress the need for community ownership of HIV and AIDS and an open discussion of taboo topics. One provider suggests the following for opening lines of communication:

We need to get other ways of conducting conversations about AIDS. We need to form a partnership with the community. It requires going through the process from not knowing, not having information, not knowing how to work the system to knowing these things and wanting to be an ambassador to those not-knowing ones. I'd like to create a whole lot of ambassadors.

An HIV-positive African American man expresses his fear over the lack of honesty in what his community is dealing with:

AIDS is overtaking us, and we need to come to grips with the reality of it. We need to be truthful with our children and honest with ourselves. Support that we need will stem from that honesty.

Many consumers and CARE Act grantees are very clear about what is working and what is not, and women are learning to speak out about what they think is most important. Initiatives that encourage women to become involved in planning and decision making must be supported and expanded. The testimonies of individuals interviewed show that they stand behind CARE Act programs that have pulled together the right mix of services in the right manner.

Chapter Five

Where to Find Out More

To find out more about model CARE Act programs that serve women and families living with HIV and AIDS, contact any of the following organizations and agencies, many of which provided useful information for the Community Research Group CARE Act study.

WASHINGTON, D.C. AND MARYLAND

AIDS Alliance for Children,
Youth & Families
1600 K Street NW, Suite 300
Washington, DC 20009
(202) 785-3564
Website: www.aids-alliance.org

The Parents' Place of Maryland
7484 Candlewood Road, Suite S
Hanover, MD 21076
(410) 859-5301
Website: www.ppmmd.org

NEW YORK (NEW YORK CITY AREA)

ACE OUT, Inc.
8 West 38th Street, Suite 806
New York, NY 10018
(212) 398-4194

Alianza Dominicana, Inc.
715 West 179th Street
New York, NY 10032
(212) 795-4226

Bronx AIDS Services
1 Fordham Plaza, Suite 903
Bronx, NY 10458
(718) 295-5605

Harlem Congregational Community
Improvement (H.C.C.I.)
2854 Frederick Douglas Boulevard
New York, NY 10039
(212) 283-5266

Hispanic AIDS Forum
886 Westchester Avenue
Bronx, NY 10459
(718) 328-4188

William F. Ryan Community
Health Center
110 West 97th Street
New York, NY 10025
(212) 316-7906

FLORIDA (MIAMI AREA)

Christ Crusaders, Inc.
2527 Opa Locka Boulevard
Opa Locka, FL 33054
(305) 769-3044

Christ Crusaders, Inc.
Broward Extension
2430 Sheridan Street
Hollywood, FL 33020
(954) 929-4262

Florida Department of Health
Office of HIV/AIDS Services
1440 Biscayne Boulevard, Suite 350
Miami, FL 33132
(305) 377-5022

Food for Life Network
4330 NE 2nd Avenue
Miami, FL 33137
(305) 576-FOOD

North Dade Health Center
16555 NW 25th Avenue
Miami, FL 33054
(305) 621-8888

South Florida AIDS Network
Jackson Memorial Hospital
1611 NW 12th Avenue
Miami, FL 33136-1094
(305) 585-5258

Stanley C. Myers
Community Health Center, Inc.
710 Alton Road
Miami Beach, FL 33139
(305) 538-8835

University of Miami School
of Medicine
Department of Obstetrics
and Gynecology
803 Jackson Tower East
P.O. Box 016960
Miami, FL 33101
(305) 243-2160

University of Miami School of Medicine
Comprehensive AIDS Program
P.O. Box 016960
Miami, FL 33101
(305) 243-5832

University of Miami School of Medicine
Department of Pediatrics
1550 NW 10th Avenue, Suite 201
P.O. Box 016960
Miami, FL 33101
(305) 243-6676

University of Miami School of Medicine
Adolescent Medicine
P.O. Box 016960 (D-820)
Miami, FL 33101
(305) 243-5880

The Village
3180 Biscayne Boulevard
Miami, FL 33137
(305) 573-DRUG
(800) 443-DRUG

MISSOURI (ST. LOUIS AREA)

B.A.B.A.A.
Blacks Assisting Blacks Against AIDS
625 Euclid Avenue, Suite 320
St. Louis, MO 63108
(314) 865-1600

The Helena Hatch Special Care Center
Washington University in St. Louis
School of Medicine
4570 Children's Place
St. Louis, MO 63110
(314) 747-2273

Metro St. Louis HIV Health Services
Planning Council
Center for HIV/STD Policy Studies
School of Public Health
St. Louis University
3663 Lindell, Room 340
St. Louis, MO 63108
(314) 977-8160

Missouri Institute of Mental Health
HIV Mental Health Services
5400 Arsenal
St. Louis, MO 63139
(314) 644-8599

TEXAS (SAN ANTONIO AREA)

Amigos Volunteers in Education
and Services
4126 Southwest Freeway,
Suite 1310
Houston, TX 77027
(713) 626-2837

BEAT AIDS, Inc.
707 Dawson Street
San Antonio, TX 78202
(210) 212-2266

Center for Health Policy Development
6905 Alamo Downs Parkway
San Antonio, TX 78238
(210) 520-8020

La Sima Foundation, Inc.
777 RL Thornton Freeway, Suite 106
Dallas, TX 75203
(214) 941-1132

Mujeres Unidas Contrás el SIDA
121 West Woodlawn
San Antonio, TX 78212
(210) 738-3393

S.A.F.B.
San Antonio Fighting Back
2803 East Commerce Street
San Antonio, TX
(210) 271-7232

Valley AIDS Council
1217 Chicago Avenue
McAllen, TX 78501
(956) 668-1155

US/Mexico Border Health Association
5400 Suncrest Drive, Suite C-6
El Paso, TX 79912
(915) 833-6450

CALIFORNIA (LOS ANGELES AREA)

AIDS Healthcare Foundation
6255 West Sunset Blvd, 16th Floor
Los Angeles, CA 90028
(323) 462-2273

AIDS Project Los Angeles
1313 North Vine Street
Los Angeles, CA 90028
(323) 993-1600

AIDS Service Center
1030 South Arroyo Parkway
Pasadena, CA 91105
(626) 441-8495

AltaMed and WomensCare East
5427 Whittier Boulevard
Los Angeles, CA 90022
(323) 869-5421

Bienestar Human Services, Inc.
East L.A. Center
5326 E. Beverly Boulevard
Los Angeles, CA 90022
(323) 727-7896
(323) 660-9680 (Hollywood Center)
(562) 436-9722 (Long Beach Center)

Common Ground
2020 Santa Monica Boulevard, Suite 190
Santa Monica, CA 90404
(310) 586-7627

Los Angeles Family AIDS Network
6430 Sunset Boulevard, Suite 1202
Los Angeles, CA 90028
(323) 669-5616

Project Angel Food
7574 Sunset Boulevard
Los Angeles, CA 90046
(323) 845-1800

Tarzana Treatment Center
18646 Oxnard Street
Tarzana, CA 91356
(818) 996-1051

T.H.E. Clinic
(The Help Everyone Clinic)
3860 West MLK Boulevard
Los Angeles, CA 90008
(323) 295-6571

C.A.R.E. Center, UCLA
Center for Health Studies
10833 Le Conte Avenue, Room BH-412
Los Angeles, CA 90024
(310) 206-6414

Women Alive
1566 South Burnside Avenue
Los Angeles, CA 90019
(323) 965-1564
Toll-Free National Hotline:
(800) 554-4876

Women's Care Center
1300 N. Vermont Avenue, Suite 401
Los Angeles, CA 90027
(213) 662-7420

Through education,
training
and advocacy,

AIDS Alliance for Children, Youth & Families
addresses the needs of **children, youth**
and families living with, affected by,
or at risk for **HIV and AIDS**.



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www.aids-alliance.org

Through education, training and advocacy, AIDS Alliance for Children, Youth & Families addresses the needs of children, youth and families living with, affected by, or at risk for HIV and AIDS.

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